

Teleconference on Health Care With Family Caregivers

March 2, 1994

The President. I want to thank you all for joining me today and for setting aside some time so that we can speak together and that together we can speak to the country about the long-term care problems in America. As we just heard, we have people from California to New York on the line, people for whom long-term care is not just a health reform issue but a real job.

One of the most important things that our health care plan is attempting to do is to make your job easier by creating a new home- and community-based long-term care program that gives people in need of assistance new choices and gives more options for long-term care, doesn't automatically push people into nursing homes to get some public assistance, and encourages people who are trying to take care of their family members to do it by giving them some help to do it. If this portion of the plan passes, for the first time we'll have a nationwide program that will give Americans, regardless of their income, some long-term care services tailored to their needs and provided in the place that they want to be most, in their own homes.

But the main purpose of this conversation today is not for me to talk but to hear from you, the people who are real experts, to understand how the approach we're taking here in Washington will affect homes and communities like yours around the country. I think it's very important that people in the Congress and the decisionmakers understand just how many Americans there are who are in the situation that you're in.

And so, let's start with Eve Lefkowitz in Langhorne, Pennsylvania. Eve is a visiting nurse who provides care for both her parents. Eve, why don't you talk to us a little bit about——

[At this point, Ms. Lefkowitz discussed her parents' health problems, her desire to keep them at home, and the cost for both in-home care and ongoing medical treatment.]

The President. Thanks, Eve. Before I respond, let me say, can all of you still hear me?

Q. Yes.

The President. One of you has been talking to somebody else while Eve was talking. You may not be able to hear her talk, but we can hear you. So if you talk while someone else is talking, then we won't be able to hear the person who is talking. So please be careful about that.

Let me say, the situation that you have outlined is one that a lot of American families are struggling with. They want to keep their parents in the home. They want to keep them around the grandkids. But they have huge out-of-pocket costs. They know if the parents go to a nursing home, especially if they just spend their resources and go to a nursing home, they can get some help.

Now, under our plan, your parents would be able to stay in your home and get many of the services that they now have to pay for themselves, including adult daycare, some help with home health services, and medications. People would have to make a contribution, all right, based on their ability to pay. So it's not free for everybody regardless of their income, but there would be a support program. In almost every case, this would be cheaper for the Government than providing nursing home care. But it will give people who have certain health problems and disabilities much greater choices about how and where they get the care. And it would enable families like you, yours, that are really close-knit, where you've tried to keep your family together, to be able to do that and succeed.

So we are going to do our best to help you. And I must say, I really admire you for doing this.

Ms. Lefkowitz. Thanks.

The President. Beth and James Crampton, are you all there from Omaha?

Beth Crampton. Yes, we're here.

The President. Beth is a 23-year-old recent college graduate who, along with her father, takes care of her mother. Why don't you talk a little about your situation?

[Ms. Crampton explained that her mother has Alzheimer's disease and discussed the family's efforts to care for her at home.]

The President. Let me ask you something. You said your father was able to attend

your graduation. Did someone come in and care for your mother during that time?

Ms. Crampton. We did. The senior companion program here in Omaha has allowed us to have a volunteer who comes in and is familiar with my mother and can help care for her. So she made special plans and came in that morning so that he could come; otherwise there would have been no way he would have seen that graduation.

The President. I really identify with this. I've had an uncle and an aunt with Alzheimer's, and I've seen what it can do to a family. And I admire you so much for staying committed, you and your father, to taking care of your mother.

One of the things that I think is important to point out, that you have just illustrated with the story that you had, particularly for families where maybe there's only one person who is caring for an Alzheimer's victim, is that there needs to be some respite care for family caregivers, so people like you and your father can at least take a break and know that you can have a lot of confidence in people who are with your mother. And our plan would provide some help to do that, would make it possible for people who are caring for family members with Alzheimer's to have people come in on a regular basis, like the person who came in for you, all across the country to provide respite care so that you would never have to fear at least having some basic normalcy in your life, that you were hurting your mother.

There are people, as you know, all across the country who are doing this now, and Alzheimer's is an issue we have to confront head-on in other ways. We also, in our health care plan, invest more than \$20 billion more into preventing and combating diseases that disable older Americans, including Alzheimer's along with breast cancer and heart disease.

So I hope that all these things will be helpful to you. And again, I want to thank you for the example you've set. I really appreciate it.

Is Goldia Kendall there?

Goldia Kendall. Yes, I'm here.

The President. From Jonesboro?

Ms. Kendall. Yes.

The President. My home State. Well, it's nice to hear your voice.

Ms. Kendall. It's good to hear you, too.

The President. Are you really 85 years old?

Ms. Kendall. I'm 85. I'll soon be 86. My husband is 89.

The President. And she's worked all her life as a cook and a nurse, and her husband is a retired factory worker and a carpenter. And he had a stroke a few years ago.

Why don't you tell us about your situation, Ms. Kendall?

[*Ms. Kendall explained that her husband also has Alzheimer's disease and described her efforts to care for him by herself.*]

The President. Yes, what we want to do is to basically reward people like you who have the courage to do what you're doing. I mean, to take your husband out of a nursing home and start caring for him all by yourself at your age is an astonishing thing. And when I was Governor of our State, I worked to try to help give people more choices in long-term care. But with the way the Federal programs work today, there is a limit on what you can do. So our plan would give people like you a chance to get some help from nurses and other assistants who could give personal care to your husband in your home while you go out and run errands and get a little break from time to time. And again, it would be helping you, but it's also less expensive for us than if your husband were in a nursing home.

Ms. Kendall. Well, yes.

The President. So, I sure admire you. I hope that I'm in half the shape that you are if I get to be 85. I really think it's very impressive that you're doing this, and it's a real tribute to your commitment to your husband. I appreciate you so much.

Ms. Kendall. Well, I'm proud of you, too. He's helpless, completely. He has a feeding tube in his stomach. I have to take care of him. He has a motor to keep air in his mattress; the doctor wanted him on an air mattress. And he's been taken care of real good. The nurse comes every week, and the aide comes 5 days a week, and Doctor Owens watches over him very close. And they all

are very pleased of me and my work, the way I take care of him.

The President. The hospital has good out-patient services there. I know about that, and that's good.

Ms. Kendall. Yes.

The President. Well, thank you very much, ma'am.

Ms. Kendall. Well, it's good to talk to you.

The President. Thank you.

Ms. Kendall. Thank you. I voted for you.

The President. Well, thank you, I appreciate it.

Ms. Kendall. I watched you on the television, every program I can.

The President. Thank you so much. It's nice to hear your voice, and good luck to you.

Ms. Kendall. May God bless you in your work.

The President. Thank you.

Is Gene Hayes there, from Fresno?

Gene Hayes. Good morning, Mr. President.

The President. Good morning, Gene. Gene is a victim of Parkinson's disease who's caring for his wife who suffered a heart attack. And I think you also are caring for your father.

Mr. Hayes. That's right.

The President. Why don't you tell us a little about that? How old is your father?

Mr. Hayes. He's 93. He'll be 94 come May.

The President. Well, tell us a little about your situation.

Wait a minute. Ms. Kendall, hold on one moment. We hear somebody talking on the line here. Everybody, please be quiet.

Okay, Gene, go ahead.

No, we can hear you talking, Ms. Kendall. Be real quiet, so I can hear Mr. Hayes.

Ms. Kendall. Oh, I see. Oh, thank you.

The President. Bless you, that's all right. Go ahead, Gene.

[Mr. Hayes described efforts to care for his wife after a stroke that left her comatose.]

The President. Do you have out-of-pocket expenses for help that you have to pay?

Mr. Hayes. Yes, I sure do. I have to have help around the clock, and there's 10 hours that we take care of her solely by ourself.

But other than that, I have a day person and a night person, and then I have a relief person that kind of helps.

The President. And you have to pay for them out of your own pocket?

Mr. Hayes. Yes, I do.

The President. You don't have any health insurance that covers that?

Mr. Hayes. No. When this happened, she was 61, and we didn't have no Medicare. We wasn't eligible for it; we was too young. And insurance, I just dropped it 6 months before; we had no insurance. So we kind of sifted right through the cracks at that point. And we've been having our retirement savings put up, and we've been using that, but it's begun to kind of dwindle away. And we had to sell several things, like our motor home and things like that. But we just take it one day at a time and just trust this will be the day that she'll get better.

The President. And you've got your father there with you too, right?

Mr. Hayes. Yes. Dad's 93, and he has heart problems. We have to give him medicine a couple times a day, and we help him with his bath. I've got to help him with his bath, and at times we help him with his clothing. But Dad's a big help, too. He sits in his wheelchair, and he watches her all the time. He never lets us forget when it's time for her medicine or it's time to turn her. He's always there to say, hey, it's a certain time. And I don't know what we would do without Dad, because he helps us, too. But the three of us just make out fine because we have a lot of help, and it seems like things have been going real well.

The President. Good for you.

Mr. Hayes. I'm thinking about a little later on, it might come to mortgaging; but we're going to take that one day at a time.

The President. I wish you would. I wish you'd come see us. Take care of yourself, sir. And thank you for your example.

Mr. Hayes. Thank you.

The President. Is Mary Hammer there from Blacksburg, Virginia?

[Ms. Hammer, who lost both her legs in an accident 20 years ago, explained that following a recent stroke she was placed in a nursing home which she did not like, and that assistance from church members and social

service agencies has enabled her instead to be cared for at home.]

The President. Thank you. You know, we wanted you to be on this call today because the local department of social services where you live has done a good job in providing the kind of personal care and companion services that you have. And I appreciate you saying such good things about them.

Mary Hammer. They're wonderful.

The President. Because what we're trying to do is to make sure all the people in the country, especially elderly people or people with children with disabilities, have access to that kind of help. We don't propose to create a whole new program or a whole new system but to build on the good things that are out there, these adult daycare services, the senior center program, the home health services, the personal care services, all these things that are working out there in the country. What we're going to try to do is to make sure that each person who needs the help can have whichever of these services they need and that they know they will be able to get the help if they need it. And you're an example of how someone can live independently, even with some significant difficulties, if that kind of help is there. And I think the kind of thing you've described ought to be available to every American citizen.

Ms. Hammer. I sure do agree with that. I've been listening to all these calls, and I'm telling you, I agree with what you're trying to do. And I just pray that this funding will keep on coming so we can keep getting this kind of help.

The President. Thank you. Well, we're going to do our best, and thanks for talking to us today. You really made a great statement, and we appreciate you.

Ms. Hammer. It's been a real pleasure. I feel honored for you to call me, Mr. President.

The President. Thank you. Well, the honor was ours today. Thanks.

Is Donna Lyttle there?

Donna Lyttle. Yes, I'm here.

The President. From South Ozone Park, New York?

Ms. Lyttle. Yes, that's correct.

The President. Thank you. Bye, Mary.

Donna, tell us a little about your situation. I think you care for your mother, who has Alzheimer's, and you work at Harlem Hospital. Is that right?

[Ms. Lyttle explained that she is the primary caretaker for her dependent mother because she can only afford limited in-home assistance and respite care.]

The President. So you have a lot of personal expenses that you just have to pay for to keep her there?

Ms. Lyttle. Yes, because the transportation back and forth to the center is a cab service that I pay for for her to go twice a week. And you have to pay for her to be taken and to be picked up.

The President. Anything else?

Ms. Lyttle. Well, I'm paying for the home attendants to come in to take care of my mother, and any other expenses that she needs are definitely coming out of pocket. Her medical expenses are definitely coming out of pocket also. But it's only through the Alzheimer's Association that I found out about the respite center. They've really been a Godsend for me.

The President. And how much do they come in and help you? Because otherwise you just put your life on hold, I guess.

Ms. Lyttle. Yes, well, my life is completely on hold. The Alzheimer's Association has been a resource for me in terms of finding channels that I need for assistance. It was through them that I found the lady that takes care of my mother during the day and about the daycare center for her. But they are—

The President. But you're paying for that.

Ms. Lyttle. Yes, I'm paying for all of it.

The President. Well, under our program, you'd have access to this kind of respite care, and you'd have a chance to at least have more of a life while keeping your mother, and the Government would provide some help based on your income. I just think that we have so many people—you've heard these other people's stories—we have so many people out here in this country who are doing their best to take care of their family members with Alzheimer's. And I think it's—clearly, with the fastest growing group of Americans being people over 80, the number of problems that elderly people have is just going

to explode in this country. And we, I don't think, can afford to have everybody institutionalized. And when people want to support their families and keep them together, I think we ought to be providing some help for it.

Ms. Lyttle. Yes, I agree. It's also pretty frightening for me because I have two additional family members that have Alzheimer's. My mother's sister was diagnosed in Barbados with Alzheimer's, but she has been placed in a nursing home. And my mother's uncle just passed in March after being home for, I believe, it's been about 15 years with his wife taking care of him and paying out-of-pocket expenses for all of his care.

The President. And you're a nurse at Harlem Hospital?

Ms. Lyttle. No, I'm executive assistant.

The President. Is that where you work, there?

Ms. Lyttle. Yes, I work at Harlem hospital.

The President. I've been there.

Ms. Lyttle. Oh, yes, I've seen the picture.

The President. I enjoyed my trip there.

Ms. Lyttle. Oh, I hope you come back.

The President. If we pass this health care plan, we're also going to make your life simpler there, less paperwork, more care.

Ms. Lyttle. That's great.

The President. Thank you very much.

Ms. Lyttle. You're quite welcome.

The President. Vera Teske, from Wheaton, Kansas, are you there?

Vera Teske. Yes, I'm here, Mr. President.

The President. And you care for your husband, and I think he has Alzheimer's also.

Ms. Teske. That's right.

The President. And you live on your family farm?

Ms. Teske. Yes, we do.

The President. Tell us a little about your situation.

[Ms. Teske discussed the problems of coping with a potentially violent Alzheimer's patient and the prohibitive expense of in-home care for someone with a long-term illness.]

The President. I appreciate your statement. I don't think I can add much to it except to point out that it's an even bigger issue for people like you, a farm family in a rural area. We have really worked hard in design-

ing this approach to make sure we're taking care of providing care in rural areas as well as more urban ones, because you've made a statement about why we need it as eloquently as anyone could.

I think—I'd just like to emphasize one more time—at a time in America when we're so worried about our young people and we say we've got to rebuild the American family and strengthen the American family, you've got all these dedicated family members who are out there who could have walked away from their family members and didn't. And it seems to me that given the fact that we're going to have more of these kind of problems as we all live longer, that we ought to be out here supporting family members and helping them to succeed and have a life not have to give up their whole life while they take care of the folks that they love. I really respect what you've done, and we're going to do our best to provide some help in this health care plan.

Ms. Teske. I appreciate my family members. They help a lot.

The President. Yes, I know you've got kids and grandkids, and that must help some. But it's still—if you're out on the farm, you need somebody to come in and give you some consistent help, too.

And you made a great statement. I wish you'd been giving it to a congressional committee. It was terrific. Send us a copy of it, will you? We took a copy of it. I'm going to send it up to the Hill. It's great.

Ms. Teske. Thank you.

The President. Is Marge Garrison there from Houston?

Marge Garrison. I'm here, Mr. President.

The President. You and your husband, I think, are caring for your daughter. Is that right?

Ms. Garrison. Yes, we are.

The President. Why don't you tell us a little about that.

[Ms. Garrison discussed the problems of raising an autistic child.]

The President. Well, I appreciate your just sharing your circumstances with us. And I appreciate the fact you've kept your child. And what you've done, I know it's been an enormous burden. You shouldn't feel bad

about saying you need help. And we shouldn't have an all-or-nothing situation. I mean, it seems to me that the people this country ought to be rewarding are people that are willing to take this level of responsibility, willing to pay something according to their ability to pay, but just shouldn't be asked to bankrupt themselves on the one hand or on the other hand just give up their entire lives. I really, really appreciate what you said. And more importantly, I appreciate what you've done.

Ms. Garrison. It may be difficult for you—you need to come spend a couple days in our home, Mr. President, and you can really see what it's like living in the house with the type disabilities that our child has.

The President. I wish I could.

Ms. Garrison. I wish you could, too. Thanks for having us today.

The President. Thank you. I want to thank all of you, Eve and Beth and James and Goldia and Gene and Mary Hammer and Donna Lyttle and Vera Teske and you, Marge. I thank you all.

In a lot of ways you're truly heroic people because you've lived by your values of hard work and commitment to your families. And I hope that your stories as they go out across the country will help us to pass a health care reform bill that will build on a lot of the good services you talked about today, those of you who have them, but make sure there aren't the waiting lists that Marge talked about and make sure that we can actually give some help to people who are trying to help themselves and their loved ones.

We can begin to do this. It will take some time to get it exactly right in America, but we've got to begin now. And that's what our plan does. And you have inspired me to keep fighting for it. I'll guarantee you, this has been a wonderful day. I thank you very much. I wish you well. And we're all in your debt.

Thank you, and goodbye.

NOTE: The teleconference began at 10:36 a.m. The President spoke from the Oval Office at the White House.

Exchange With Reporters Following the Health Care Teleconference

March 2, 1994

Health Care Reform

Q. Mr. President, what do you think of the polls that show that your health care—going down the drain—you may not be—

The President. That's not what they show. One of the polls shows the serious concern level going up. How could it be otherwise? Look at the millions and millions and millions of dollars that have been spent by interest groups to trash the plan, people that don't want to assume any responsibility for their employees, people that don't want to assume any responsibility for providing basic health care, and people that think they can get just a little better deal.

It's no accident—I will say this: We've tried for 60 years to join the ranks of the rest of the world and give everybody good health care in this country, and it's no accident that it hasn't happened. It's because change is difficult and the people who are doing well in the present system devote a lot of money and time to stopping the change.

But I'm still actually pretty optimistic about this because what happened is, every time I get a chance to speak to the American people about it, support goes back up, like it did at the State of the Union. Then we go through a long period of where nothing is happening in the Congress and everybody is kind of maneuvering for position legislatively and we're being attacked. And we don't have as much money to spend as those who are spending money against us on the ads and all that sort of stuff. So these things will happen.

The thing that encourages me is I talk to more and more Members of Congress that seem to have a very practical attitude about this and want to find a way to give everybody health security, some system of guaranteed insurance on health care without taking away the good things that we have now. And that's what we're going to do. And I actually feel, based on my conversations with Members of Congress and the impact that we still get whenever we go out and talk about this specifically, like when we went to Connecticut